

# England And France Set Examples Of Home Care Programs

by Allen Goldberg, MD

The issues we will discuss today are based on recent history — the world-wide polio epidemic of the 1950s which led to the development of new approaches to medical technology and health care organization. The epidemic featured a severe form of polio that took the lives of countless children and adults, often in their most productive years. People died because of paralysis of their respiratory muscles. The realization of the need for artificial ventilation led to the development of the modern techniques of upper airway management and mechanical ventilation such as tracheostomy and positive pressure ventilation. This new technology resulted in a reduction of mortality from respiratory failure from 90% to 20%; however, many of the survivors remained dependent on ventilatory assistance — some for a lifetime.

The comprehensive medical needs of the polio survivors required an interdisciplinary health care team of physicians and allied health personnel. A new approach to the medical treatment of chronic illness and long-term disability was developed. This medical challenge created the basis for the concepts of health care including administration, clinical methodology

and research as featured in the system of specialized respiratory (polio) care centers.

One success of these specialized centers resulted from research: The discovery of the polio vaccine. This discovery in 1956 of an effective preventative measure against polio all but eliminated one of the medical scourges of all time. But the "polio story" did not end there for the survivors. Some had to remain in institutions for undetermined periods of time because they depended on breathing machines and had nowhere else to go. These were the first ventilator-dependent children and adults.

They discovered new approaches to their care and answers to their needs which were major dimensions of "self-help." Working with professionals, families, volunteer organizations and friends, they created outreaches from the regional polio centers such as home care and other community-based living alternatives and support services. The centers and home care resulted in a tremendous financial savings and a greater degree of independence and self-sufficiency than was ever dreamed possible for people so severely disabled.

Since the creation of modern

critical care and rehabilitation medicine from the polio experience, countless people with serious illnesses have survived who would have died years ago. Some of these survivors now constitute a new population of people dependent upon life-supportive technology. Examples include high spinal cord injury, severe muscular dystrophy, and a variety of other neurologic, muscular and pulmonary diseases that previously resulted in early death. These survivors must needlessly and inappropriately remain in institutions at enormous cost in economic and human terms because they have no alternatives.

This is only part of the current crisis in health care delivery. Excessive health care costs have mostly exceeded our ability to pay. In 1980, the health sector claimed 13% of every non-defense federal budget dollar. The national health expenditures approximated \$70 billion in 1970 and \$247 billion in 1980. Projected costs for 1990 are over \$1 trillion! In 1970, national expenditures accounted for 7.2% of expanding gross national product and, in 1990, it is projected to account for 15%.

Our medical reimbursement system is set up to pay for all acute

care costs, but it is not designed for financing home care or other suitable alternatives. Unless we design better operational systems and more adaptable reimbursement mechanisms, we face the danger of curtailment of services and a resultant decline in the quality of life (or even survival) of many disabled people.

In the United States, the possibility for home care or alternatives for chronic respiratory disabled children and adults are limited to a few demonstrations. For adults, existing facilities include respiratory rehabilitation centers (Goldwater Memorial Hospital Howard A. Rush Respiratory Rehabilitation Center in New York, The Institute of Research and Rehabilitation in Houston, TX, and Rancho Los Amigos in Downey, CA) which evolved from their polio experience, some skilled nursing facilities without rehabilitation services, and scattered home care experiences. Concerning children, home care demonstration projects have been implemented in Massachusetts, Texas, Pennsylvania, Illinois, and other states. A major problem exists, however, because we don't know where all of these children are or who is dealing with them. A need exists to document and register this information.

I have been aware of the regional approach to ventilator-dependent persons in England and France. This year, I was given the opportunity by the World Rehabilitation Fund to do a comprehensive study on these programs. The International Exchange of Experts and Information Program has been funded by the National Institute of Handicapped Research to acquire knowledge of exceptional programs, practices, and policies in other industrialized nations to enhance the knowledge base of rehabilitation in the United States. I will now

present a synopsis of my study, describing the programs and giving their histories, analyzing operational systems, and suggesting their benefits.

### **The English solution — the "responaut program"**

The first program concerns "responauts" who are ventilator-de-



*Allen I. Goldberg*

pendent persons who are severely physically disabled and live independently in England. They coined the term "responauts" themselves because, like the astronauts, they ventured into the unknown. The original responauts were polio survivors. In 1965, some of these people stayed at home without any established system of services and some remained in polio centers which were closing.

At the same time, the acute intensive care unit just developed by Geoffrey Spencer at St. Thomas' Hospital, had long-term ventilator-dependent survivors. To serve

both populations, the Phipps Respiratory Unit (PRU) at the South Western Hospital was created. From this location the responaut program evolved as an organized series of services available to anyone in England who depends upon prolonged mechanical ventilation or who has a respiratory disability that requires referral to Dr. Spencer. The establishment was a collaborative effort among the health care professionals, patients and families, hospital administrators, and government authorities. The responauts initiated public, private and government involvement which resulted in "Responaut Study," a major success of self-help.

The "Responaut Program" consists of the following services:

- Comprehensive medical/rehabilitation care in the PRU
- Planning for a safe discharge to home or a variety of community alternatives
- Home care, either provided by one of 17 PRU attendant staff, who live in the home of responauts, or community-based caregivers, provided by a government agency or government fund
- Home maintenance service of all respiratory, technical and personal needs on a regular and emergency basis

The PRU remains the base unit because this arrangement provides security for the patients, professionals, and administrators, and guarantees standards of care and quality-assurance. It also provides the most coordinated operational basis as well as a medico-legal basis for the protection of all involved parties. The PRU is where patients are first admitted for evaluation, stabilization, and eventual discharge. After the 1973 Responaut Research Project, all participants could go home. This allowed the PRU to function as a

short term unit for more acute illnesses, minor adjustments in prescriptions and outpatient assessments. The hospital patient length of stay was 568 days in 1968; 18 days in 1975; and 11.9 days in 1983. Today, even though the responauts are home, they are still the charge of St. Thomas' Hospital. The PRU team leaders which serve the patients include a physician, nurse, physical (respiratory) therapist, and social worker. The current health care/social legislation in England provides a complex reimbursement policy, partly statutory — partly discretionary. The social worker coordinates a financial program for each responaut among a variety of options from local and health authorities.

To complement home care, the PRU home maintenance service (which includes three medical technicians, three service vehicles, a hospital-based workshop and inventory of major equipment and supplies) coordinates a very personal service from the PRU. The service does routine maintenance of the equipment and minor/major emergency replacement. Since its onset, 411 patients have been served by the "Responaut Program;" as of June 1983, 223 persons were benefitting from it.

Because not all responauts have families to go home to, they require other options and services in order to live somewhat independently in the community. These services were not created specifically to meet the needs of the responauts; however, they take advantage of the existing resources designed for other purposes. Examples include the Netley Holiday Home (Respitel Care) and the Chailey Heritage Hospital and School (education and rehabilitation engineering).

The financial basis of the responaut program is the original arrangement between St. Thomas'

Hospital and the Department of Health and Social Security; legislation, which provides both statutory and discretionary funding; and supplemental funds from a variety of charities.

### **The French approach — the regional association**

As in England, the solution for the ventilator-dependent person in France evolved from the efforts of multiple concerned parties. These people looked for community options for groups of polio survivors who faced no other choice but prolonged institutionalization. The former polio centers in which they lived, evolved into intensive care and rehabilitation centers. The concept created was "ventilator assistance at home."

Two not-for-profit organizations helped to implement the concept for the polio survivors. The Association of Mutual Help for Polio and Handicapped People (ADEP) and the Association of the Lyon Region for the Fight Against Polio (ALLP) evolved into the "core" of the cost effective regional solutions for ventilator and oxygen dependent persons in the greater Paris and Lyon regions. They also formed the base for a new national organization, the National Association for Home Care of Respiratory Insufficiency (ANTADIR). This national organization deals with issues such as mass purchasing, national statistics and surveys, collaborative research, and information exchange.

ADEP was initially created to improve hospital life and later developed as a means to send patients home or on to independent living alternatives. It was created by and for the polio survivors who had to remain forever in the Raymond-Poincare Hospital, Gareches, France. It is now a multipurpose

not-for-profit organization contracted to provide home ventilator services, community-based living alternatives for ventilator-dependent adults, and documentation of information for the demonstration of an effective self-help group which has expanded to help others. As ADEP grew to meet existing demands, it received requests from the government to serve as the model for development of other regional associations and to develop a national organization to deal with issues appropriately. Currently, ADEP serves over 650 persons.

The services of ADEP are described in a contract between three major reimbursement agencies and ADEP. This arrangement is the basis of all negotiations with any other reimbursement resources. The prospective reimbursement package permits ADEP to provide the following services:

- Acquisition, delivery, installation of a large variety of durable medical equipment
- Oxygen (tank/extractor)
- Provision of all required accessories
- Routine/emergency home maintenance service
- Required electrical modifications for equipment/home
- Required installation of telephone
- Communication with medical resources (community, institutional); regional coordination of services/care
- Administration of the program (quality assurance)
- Evaluation of the programs (accountability)

ADEP Home Care Program is divided into four services: admissions, maintenance (technical service), medical social service, and administration. The admissions process creates all necessary documentation required for

## **The current health care/social legislation in England provides a complex reimbursement policy, partly statutory – partly discretionary.**

each new prescription of service such as medical and administrative records, requests for equipment loan or purchase, reimbursement, communication with third party sources, etc. They also contact an ADEP nurse who is initially involved with patient education and preparation for home.

The home maintenance service consists of 10 persons including secretaries, staff, technician, inventory persons, and a driver. Eleven vehicles stand by, fully stocked and prepared to make major repairs. Six of the vehicles are radio-dispatched, making an emergency service possible by an on-call technician. All the technicians are qualified in mechanics and/or electronics and have had on-the-job training. Preventive maintenance is provided on a bi-monthly basis. The service guarantees a greater quality assurance, decreased risk, increased security and it reduces costs.

The medical social service provides medical evaluation and follow-up, supervised by two physician specialists. These physicians also make home visits when requested by ADEP nurses or technicians. The ADEP nurses visit the patient in the hospital to determine what equipment is needed and to plan required inventory.

The accounting and administration of ADEP Assistance is centralized with several designated administrative assistants and accountants who report to a director. The center keeps all records, statistics and creates monthly accounts of all activities, equipment and patient status. This organized documentation of services facili-

tates communication with the sources of third party payment.

The founder and president of ADEP, Andre Dessertine, created the organization as a means to help others help themselves and instituted the philosophy which implements:

- Greatest possible degree of independence compatible with physical status
- Reinsertion into urban setting for a full opportunity for a social life
- Medical security to degree required by the medical condition

ADEP emphasizes medical security to reassure medical personnel, public authorities and the disabled person that alternatives to institutionalization were appropriate. In special housing set up for the disabled (Foyer d'ADEP), each ventilator-dependent person has several methods to reach personal care attendants or medical staff who are on call. The medical care is given by a combination of health care professionals and well trained, highly motivated personal caregivers.

In 1964, the ADEP Documentation Center was established which stored information concerning the studies and experiments which aided the disabled. The center was officially established as an Information and Documentation Service in 1974, and currently available to anyone concerned with issues related to disability. Today the service receives over 100 French and other language periodicals from multiple sources. The information is systematically classified according to defined themes. The center has

also proven to be helpful in research.

The other organization which exists in France, the ALLP (Lyonnaise Regional Association for the Fight Against Polio) is also a not-for-profit organization which coordinates the total program and services required by the ventilator-dependent persons in Lyon and the surrounding areas. It, too, as the services in London and Paris, originally served the polio survivors.

During the polio epidemics of the 1950s, the Croix-Rousse Hospital in Lyon was designated as the center of expertise for the management of acute respiratory failure. Care was provided in a polio unit: The Service of Professor Sedallian. When the hospital reached capacity in the mid 1950s, it was thought the ventilator-dependent patients might do better at home. A mechanical device was developed (Vincent-Gandot) and the first patient went home in September 1960. That person is still at home and is living a full life with his wife and family.

In the first years of the program, the hospital staff volunteered their services. In 1961, the ALLP began to send home non-polio ventilator-dependent patients. Later in 1967, the leaders of ALLP negotiated a contract with regional reimbursement authorities who provided a prospective payment of \$5 per patient. Most recently, the ALLP has begun to serve oxygen-dependent persons at the request of the Regional Social Security.

The original polio center is now a multidisciplinary adult ICU with an acute care and chronic respira-

## **"In England, charities play a strong advocacy and political role, and have a great impact on government policies for the disabled."**

tory rehabilitation section, both under the direction of Professor Dominique Robert. It plays a major role in the preparation of patients, families and caregivers for the transition to home.

The ALLP is located on the hospital grounds of the Croix-Rousse, adjacent to the Pavillion Paul Sedallion. The physicians determine the standards of respiratory care and lend quality assurance to the program. Primary medical care is given by a local physician. The RN role is determined by the needs of the patient at home. The nurse understands the patient's status in each situation. The visiting nurse makes home visits where her role is to implement quality assurance, continuity of care and to evaluate all problems.

The medical technician has responsibility for both the equipment and the medical and psychological needs of the client. In addition to pre-scheduled routine maintenance visits, the technician is available at all times for emergency needs. These people are factory-trained and are responsible for the repair of all equipment.

The services of the ALLP are spelled out in a contract which features categories for prospective reimbursement. The rate depends upon the need for ventilation, tracheostomy care, and oxygen, including the method of oxygen administration as well as the source. The prospective charges range from \$4/day to \$22/day with a mean rate of \$9/day. The contract spells out the specific objectives of the program, the criteria for the program, the daily prospective

rate, the description of covered services and personnel, and the interrelationship of involved parties. It also specifies required documentation and explains the role of an advisory committee. Attached to the contract is a complete home ventilator care protocol. Currently, ALLP serves over 450 persons.

Another essential component of the successful transition from institution to home in the Lyon regional program is the intermediary (secondary) center. It permits the fullest preparation and education of each ventilator-dependent person at a location with significant cost reduction. Of the three centers in the Lyon region, Bellecombe is the largest with a capacity of 130. The average length of stay at this transitional care center is 55 days, during which time the patient is well-educated in his/her equipment and self-care.

Despite the fact that the ALLP existed, a few ventilator-dependent polio survivors remained for years at the Croix-Rousse Hospital. As an alternative to prolonged institutionalization, the ALLP followed the model of ADEP and created the Foyer d'ALLP. All of the survivors obtained education but they could not earn an income or they lost their government benefits. However, they used their education in managing their lives and their homes.

The ADEP and ALLP do not provide primary caregivers. In France, it is impossible to have 24-hour nursing surveillance; therefore, ventilator-dependent persons at home require a highly committed family to participate in care. The

reasons for unavailability are that there is simply an inadequate number of available health care professionals, and those who are available, prefer to work independently at a higher rate. There are times, however, in the home when situations arise and the family must call in help. At these times, it is possible to have a new type of personal caregiver. These people may have two roles: 1) Domestic (housekeeping, feeding, and cooking); and 2) Health (physical care, personal hygiene). For chronic respiratory patients, often the duties require medical expertise. The Association provides these caregivers with 8-15 days training for this purpose.

The "auxiliaire de vie" as the caregivers are known, is a recent development in France. The position has just risen to a professional status by federal regulation.

### **Developing an American approach**

To help apply these programs from England and France to the national-regional-local realities in the United States, it is necessary to look at the reasons why these programs were successful.

In England, charities play a strong advocacy and political role, and have a great impact on government policies for the disabled. Charities develop new services and programs based upon demonstrated needs. Government and charities work together in the process of mutual cooperation.

In France, all programs are coordinated by not-for-profit voluntary organizations (associations) which provide quality assurance, case-

**"In France, all programs are coordinated by not-for-profit voluntary organizations (associations) which provide quality assurance, case-monitoring, and accountability."**

monitoring, and accountability, resulting in cost containment. They are small, flexible, permitting multiple interdependent roles for members.

It is also helpful to look at the evolution of these services and their reimbursement. In England, all programs began with a leader, a small group of concerned people, and private money. Each had an initial success which captured the government leaders' attention and later led to government support, commitment, and appropriations for the program. In France, the programs evolved from successful initial demonstrations followed by negotiation with multiple reimbursement resources. Once a prospective rate for defined services was established, the operation grew to meet expanding needs.

The funding of England's home care services is supported with public funds based upon legislation. Ventilators at home are prescribed by a physician and must be provided by law. Charities supplement costs not covered by public programs. All health care and personal service expenditures are part of a finite allotment which must be divided among multiple competitive and worthwhile organizations.

France's funding is based mainly upon public monies. Reimbursement is distributed by agencies which represent a region and/or vocation. Multiple interest groups compete for a finite sum of health care funds, somewhat like the public/private health care financing in the United States. The reimbursement agencies have cho-

sen to utilize the regional association as responsible case-managers.

The attitude toward disability in England seems to be one of concern, due to adequate media coverage, parliamentary discussion and effective advocacy by charities. This favorable awareness also exists in France due to similar reasons. In addition, France established an organization to deal with important public policy issues concerning disability.

What began as the "Responaut Program" in a local area in England grew to national scope due to the expertise developed and the number of persons who required special services. Programs in France were designed to meet geographic, political and economic realities. As the demands for the service grew, a study was done which led to the creation of a national organization. There now exists some concern about regional/national role definitions.

In both England and France, a base unit of excellence (health care institution) guarantees a high standard of care. The base unit also serves as a facility for the stabilization of the patient, initial family education, training and preparation for home, and for meeting subsequent health care needs. Both English and French programs highlight personal, high quality home care surveillance which guarantees competent and reliable preventive maintenance, emergency repair service, and communication to all involved persons.

The equipment in both countries

is simple and reliable. Home ventilators/respirators do not have to meet dictated standards and regulations. The quality is assured by the home-unit. Also, in both countries, malpractice suits are less likely because legal contingency fees are not incentives, and the services provided are quite personal.

### **The United States reality**

The United States is larger geographically and more complex socially than England and France. Uniform health care and personal service delivery is far more of a challenge. Services for the disabled are currently determined politically more by state and local policy than by regional or federal regulations or legislation. Quality of care often is more a result of social or economic class — or even chance!

The economics of health care delivery are vastly different than during the past three decades. During that period of post-war economic boom, there was an enormous growth of the health care system. There were vast qualitative and quantitative improvements in the provision of health care. This was only possible due to the nation's overall economic well-being in the '60s and '70s. Much of this was spurred by the comprehensive entitlement programs which permitted health care by a cost-reimbursement policy with no limit in sight. All national opinion polls showed strong public support for improving and expanding health care during this period — at any cost.

## **"Unless we design better operational systems and reimbursement mechanisms, we face the danger of curtailment of services, denied health care, and decline in the quality of life?"**

However, since the mid '70s, we have had a vastly different situation. The nation itself experienced a deterioration of economic performance by indications such as slowed economic growth, continued inflation, and reduced purchasing power of the consumer. This was accompanied by a change in public mood. Many people found it difficult to handle expenses of routine health care. People became concerned about economic issues and were opposed to a limitless increased spending on health care. At the same time, the public demanded the right of access to appropriate services.

There has been a real decline in public spending for health care and in methods of reimbursement. (Change from "Cost-reimbursement" to fixed, pre-set payment determined by "diagnostic related groups," to "prospective payment," to "preferred provider organizations" who respond to "requests for proposals.") Often these systems do not have built-in flexibility required to adapt to unique solutions and rapidly changing conditions.

Also philanthropic spending for health care has been reduced. The private sector has responded to a "hidden tax shift" (moving the burden of reimbursement from public to private sources) with a retrenchment, and a re-thinking of who, what and how they will reimburse present health care delivery and new proposed models.

Hospitals, our major provider of care since the 1960s, now face an economic austerity which will limit new program development

and expansion of services. At the same time, a huge private sector home care industry is preparing to serve the disabled. It is estimated in Naisbitt's book, *Megatrends*, that the growth of the home health care industry will be 20-fold over the period from 1970-1990.

Major public policy decisions are about to be made concerning home health care. Up to now, private and public reimbursement authorities have not yet developed or adapted mechanisms to meet the home care equipment and service funding requirements. There are gross inequalities based upon the financial resources of various social classes. All involved are concerned about issues such as quality-assurance and malpractice-liability, a major hidden cost of health care in America. Policy experts appropriately wonder if the trend to deinstitutionalize will lead to better health care at less cost.

Throughout my study, I attempted to ascertain if there was applicability of the English and French models in the United States. I believe that reimbursement and liability are the major barriers to developing appropriate, cost-effective, personal services for severely-disabled persons.

Although the major reimbursement systems for European operating programs I observed are public, there are certain elements that make my observation abroad applicable to the United States:

- All good programs start privately through charitable or voluntary organizations
- All evolve with the patience and

cooperation of multiple involved interests working together in partnership (government, consumer, organizational, professional)

- All reimbursement issues have similar conflicts. The same issues are within "government systems" (finite allotments) as are in a private/public system

- All good programs must be initiated in small scope with a defined focus. They must demonstrate their worth before growth and government support.

- Most programs can adapt to meet multiple needs and hence optimize available resources.

The current reality in the United States is that excessive health care costs have nearly exceeded our ability to pay. Furthermore, they are no longer acceptable to third party payment sources, public policy experts, and the general public. New concepts and options are being considered including home health care, increased consumer involvement, prospective reimbursement, and a wholistic approach to wellness. All this demands a reassessment of how we as health care professionals play our role to the ultimate benefit of those we care about: Our patients.

The English and French programs have independently shown that the complex challenges of the ventilator-dependent person can be creatively faced and met. When caring people join and find common concerns for mutual benefits, conflicting problems become opportunities for positive interaction. By the right process, solutions can meet all needs. Health care institu-

tions can be better utilized for their appropriate mission, and the health care professional's time can be better directed. Money can be saved by utilizing motivated, less expensive personnel who can work with qualified allied health personnel, and consumers can have a high quality, personal service which meets their needs because they have had input into the design. Third party payors can have quality assurance and competent case management resulting in cost containment while government officials can meet their political agendas. Voluntary (not-for-profit) organizations can play an important and worthwhile role of social responsibility.

Currently in the United States,

there are many organizations that care about people (religious service organizations, and community based voluntary groups such as Rotary, Lions, Kiwanis, Veterans' groups, etc.) and have "grass roots" resources. Many such organizations search for new directions and challenges. They can provide personal, local support. However, the funding required is beyond the capability of any voluntary organizations. The cost of home care services is still high. Funding must be found from multiple sources, including public and private sector monies which can be channeled responsibly by a well-defined, well-coordinated reimbursement process.

Unless we design better opera-

tional systems and reimbursement mechanisms, we face the danger of curtailment of services, denied health care, and the resultant decline in the quality of life, or even survival, of some disabled persons. Past demonstrations in America, and those described in this report from abroad, have proven that a higher quality of care can be more appropriately provided in the family or another community option at a cost savings. We can provide better services for less money. The solutions of the problem of the ventilator-dependent person will have far-reaching and universal benefits. The solutions can have appropriate application to many other complex health care and societal problems we face today. ●